

May 15, 2020

The Honorable Alex Azar
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, DC 20201

Roger Severino
Director
Office for Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue S.W.
Washington, DC 20201

Dear Secretary Azar and Director Severino:

The undersigned organizations represent millions of patients who may be at increased risk of complications related to COVID-19, including those with cancer, cystic fibrosis, epilepsy, serious lung diseases like asthma and COPD, kidney disease, and other conditions. We urge the Department's Office for Civil Rights (OCR) to issue additional guidance to make clear that state emergency triage guidance that would limit or restrict access to life-saving care for certain patients with underlying conditions due to the COVID-19 pandemic violate federal antidiscrimination laws.

Our organizations applaud the actions that many states have taken to flatten the curve and acquire more life-saving ventilators and other critical equipment. However, if we reach a point where emergency triage protocols must be activated, states, hospitals and health systems need strong, clear guidance from OCR.

We appreciate the joint HHS/OCR bulletin issued on March 28, which says "persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities or age. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."¹

Notwithstanding this bulletin, a number of states are developing COVID-19 action plans and toolkits that provide guidance to medical professionals on how to create emergency triage portfolios in regards to scarce health care resources. We have found that some of these guidances use pre-existing diagnoses to determine who receives care, discriminating against the patients we represent with underlying health conditions. As states develop these action plans, we urge HHS and OCR to continue to make clear that any plan for allocating scarce medical resources during the present emergency, or any future one, ensures that *all* patients—regardless of underlying conditions—are equally eligible for treatment based on their current clinical presentation.

Guidance should include the following:

- Decisions about who receives care should be based on the patient's likelihood of responding to a treatment.

¹ HHS Office for Civil Rights in Action. BULLETIN: Civil Rights, HIPAA, and Coronavirus Disease 2019 (COVID-19). Mar. 28, 2020. Available at <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

- All persons should be qualified to receive lifesaving care, regardless of the presence of an underlying condition or advanced age.
- States should be transparent in their guidance to hospitals and health systems to ensure public accountability.

Our organizations thank you again for the OCR guidance from March 28 and encourage additional guidance to create more clarity for states and health systems. Our organizations are happy to provide a patient perspective on this important issue. For more information or to discuss further, please direct your staff to contact Stephanie Krenrich at the American Cancer Society Cancer Action Network at Stephanie.Krenrich@cancer.org.

Sincerely,

Alpha-1 Foundation
Alliance for Aging Research
American Cancer Society Cancer Action Network
American Kidney Fund
American Lung Association
Arthritis Foundation
Association of American Cancer Institutes
Bazelon Center for Mental Health Law
Cancer Support Community
CancerCare
Children's Cancer Cause
Chronic Disease Coalition
COPD Foundation
Cystic Fibrosis Foundation
Debbie's Dream Foundation
Epilepsy Foundation
Family Voices
Fight Colorectal Cancer
FORCE: Facing Our Risk of Cancer Empowered
Global Liver Institute
GO2 Foundation for Lung Cancer
Harm Reduction Coalition
Hemophilia Federation of America
International Myeloma Foundation
KidneyCAN
LUNGeity Foundation
Mattie Miracle Cancer Foundation
Melanoma Research Foundation
Mended Hearts & Mended Little Hearts
Muscular Dystrophy Association
National Alliance on Mental Illness

National Cancer Registrars Association
National Coalition for Cancer Survivorship
National Health Council
National Hemophilia Foundation
National Kidney Foundation
National Organization for Rare Disorders
National Patient Advocate Foundation
Oncology Nursing Society
Prevent Cancer Foundation
Pulmonary Hypertension Association
Society for Immunotherapy of Cancer
Susan G. Komen
The AIDS Institute
Triage Cancer
WomenHeart: The National Coalition for Women with Heart Disease
ZERO - The End of Prostate Cancer